

IMMUNIZATION REGISTRY FOCUS GROUP STUDY
October 19, 1998
Monolingual Cantonese-speaking Chinese Group (Lower education)
Pasadena, California
Moderator: Susan Chow

SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

I. Prevention

Diseases mentioned:

- Cancer and any other life-threatening disease

II. Immunization

A. Reasons not to get vaccinated

- Respondents mentioned a lack of funds to pay for the immunization. Due to a lack of funds, some parents might feel that they could avoid immunizations for their children.
- They said that some parents might see immunizations as optional because some diseases (i.e. chickenpox) do not result in serious or permanent damage.

B. Reasons to get vaccinated

- It is a protective measure.
- They are good for the children and have been researched by professionals.
- No vaccinations means no school.

C. Ways parents are reminded of vaccine schedule

- Schedules given at the birth of their children
- School reminders
- Notifications from family doctors
- Chinese newspaper (especially for seasonal shots, e.g., flu shots)

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

Positive reactions:

- Respondents said that storing this information was a good idea. They said they would not have to worry about the information being lost. They also felt that this would be a convenient, time-saving way to obtain immunization records for school enrollment purposes.

- Participants liked the easy accessibility of information stored in one, central place.

Negative reactions/concerns:

- Overall, respondents felt the registry was a good idea if the information was put in correctly and if children's names and records were not confused.
- Some respondents wanted to know who would be maintaining the records (i.e., their doctors or whoever).
- A few respondents were not certain if such records could be easily kept.

Other concerns:

- Several respondents wanted to know if past serious illnesses (i.e. heart problems) and allergic reactions could also be kept on the record.

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Respondents thought that it was standard to include the type of vaccine, the date administered, manufacturer and lot number in the registry.
- Some respondents felt that personal information was beyond the scope of the registry.
- Others objected to the inclusion of the mother's maiden name and considered this an invasion of privacy, and poses a security risk because usually your bank account requires your mother's maiden name.

B. Reactions to including home address and phone number

- Overall, respondents felt it would be all right to include their home addresses and phone numbers in the registry information.

C. Reactions to including parent or child Social Security number

- There was no consensus with regard to inclusion of Social Security numbers. Some respondents felt it would be appropriate to include the child's number. Others considered Social Security numbers as personal information that should be kept confidential. Overall, they did not really see the relationship of the social security number with a registry such as this.
- A few respondents said they were concerned that someone might obtain their Social Security number and use it for illegal purposes.

D. Reactions to including healthcare members enrollment (WIC, MediCal numbers)

- No respondents said they disliked the inclusion of these numbers. Some participants, however, thought the inclusion of these numbers was unnecessary and served no purpose.

III. Access

A. Who should have access

- Schools
- Parents

B. Who should not have access

- People who do not work in health-related fields
- People working in health areas not related to immunization
- Insurance salespeople
- Businesses

C. Reactions to idea of linking registry by computer to other health information systems

- Respondents said that computer links with health-related organizations would be appropriate.

IV. Consent and Inclusion

A. Reactions to “opting out” option

- Respondents like this option best. They said it would be good for their children. They liked having the opportunity to choose.
- Some respondents wanted to know exactly what information would be included before they would be able to make an informed decision.

B. Reactions to “consent” option

- Some respondents said this option was very controlling.
- Others felt this option would not be beneficial for children whose parents are lazy or absent-minded.

C. Reactions to “automatic” option

- Respondents did not like this option. One of them said that this option would be inclusion by force which “is not the American spirit.”

SECTION 3: WRAP UP AND CLOSING

I. Most important benefit(s) of registries

- Records would never be misplaced.
- The registry would be a record that would be trusted.

II. Greatest concern(s)/biggest risk(s)

- Privacy
- Confidentiality
- Assurance that information cannot be accessed by unauthorized persons or groups such as profit making types of companies like insurance companies.
- Possible confusion between similar names

III. Influence of healthcare provider in decision to participate in a registry

- Overall, most respondents said they would do what is best for their child. Some felt their doctors would tell them the most beneficial action to take; others wanted to decide for themselves.

IV. Suggestions/comments to people who are responsible for how system works

There should be a comprehensive management system that is convenient and effective.

Please keep a record of severe reactions the child has had to the vaccines.

The child's immunization information should be shared with the school.

The records should be accurate, absolutely accurate. The records of one child should not be mixed up with those of other children. The information should be up-dated to match new medical developments.